

Social Support Networks of Aging Persons with Intellectual Disabilities

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SCIENCES**



Agenda

Introduction

Positive psychology approach to supporting aging adults with ID (van Heumen & Heller, forthcoming)

Social relations, aging and ID

Experiences of aging adults with ID

Supporting social relations

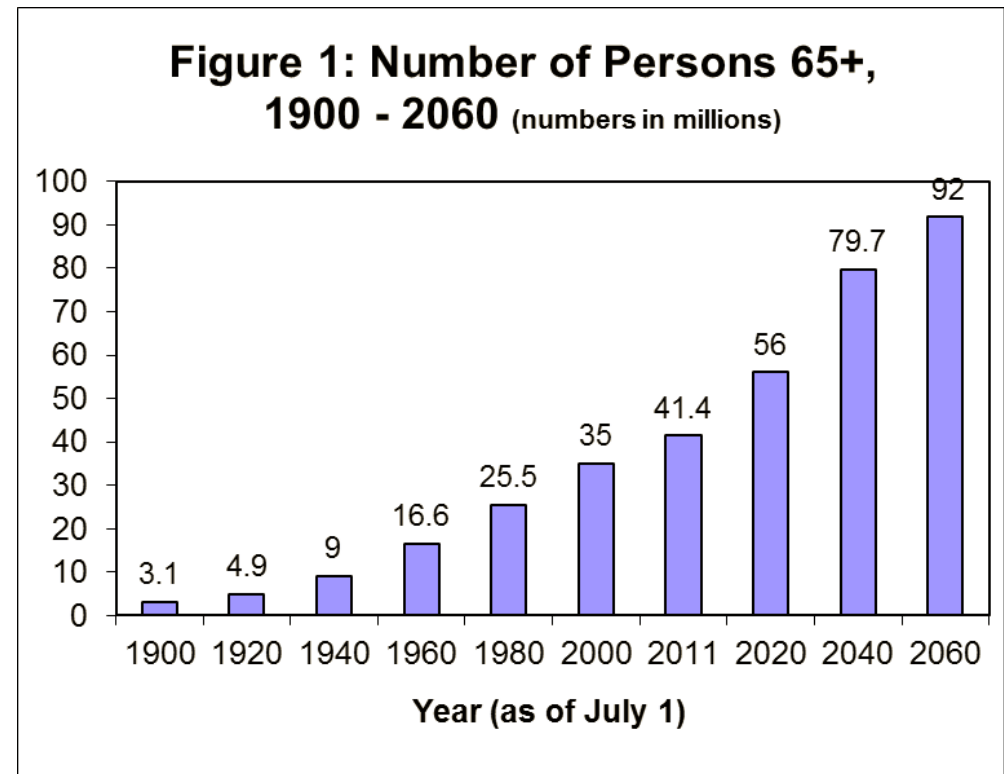
Introduction

The aging of our population

Increased life expectancy

Aging in relative terms

Aging in absolute terms



(AoA, 2013)

Aging of people with ID

Largest group of people aging with lifelong disability (Bigby, 2004)

Increasing life expectancy

- 641,000 people with developmental disability over age 60 in US.
- Numbers to double or even triple by 2030 (Heller, 2013)

Priority population

Chronic health conditions

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graph TD; A[Chronic health conditions] --> B[Long term services and supports]; B --> C[Meaningful retirement]; C --> D[End-of-life care];
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Long term services and supports

Meaningful retirement

End-of-life care

Positive psychology approach

Positive psychology approach

Focus on creating positive and meaningful aging experience

Application of life course perspective to aging/ID

Interventions informed by experiences of aging adults with ID



'Successful aging'

Defined traditionally as
aging *without disability*

Example of ableism

What does successful
aging look like for people
with lifelong disabilities?



Aging well for adults with IDD

Living on your own terms

Adding value to society, family or friends

Maintaining health and cognitive function, maximizing mobility, retaining function, and reducing the impact of chronic disease/dysfunction (Heller, 2004)

Life course perspective

Aging is a lifelong process

Life experiences impact health and well-being in late life

Late life transitions challenging for adults with ID

Social relations, aging and ID

Social relations in late life

Social relations support aging well (Cavanaugh, 1999)

Supportive networks develop across the life course

Supports and opportunities needed to develop and maintain a supportive social network

Inclusion requires connection to others

Social relations of older adults with ID

Social networks of people with ID generally small

(Lippold & Burns, 2009)

Indications for prevalence of loneliness in this population

Social opportunities and personal skills of importance

This population has less strong advocates and less robust networks

Experiences differ based on generation and residential history

Greater focus needed in practice

Experiences of aging adults with ID

Aging experiences of older adults with IDD

Functional aging more important than
chronological age (Haveman et al., 2009)

Aging understood as physical decline

Desire to be active

Experience of losing loved ones (Brown & Gill, 2009; Burke
et al., 2014; David et al., 2015)

Betty

“Growing old means that you are settled and know what you are doing. I am more kinder, I get along a lot better. I have friends I am happy with and that I do things with.”

“You feel older, in your bones... Your body. It changes. You get wrinkles...and your face changes a little bit...I hope I will always have this look but I won't, I will be old, get older and change and everything. My face, and I am happy. When I change, I am still happy.”

“I wish that I keep going happy and that I don't feel old and that I am not in a wheelchair. My dad walked with a cane and so did my mother.” (F, 66)



(Be)longing in late life

'I feel alone a lot since my mother died. That happened a long time ago...Now I ain't got nobody....I ain't got no family or nobody. Oh, it is a hard thing to say....It is all you think about.'

-William, 71 years old, African-American man

Most, most everybody is gone, except for my brothers and sisters..... Thank God that I still have some.'

-Lucy, 51 years old, Caucasian woman

'I would rather be in heaven with mom and dad. I want to forget... I wish it never happened [death of parents]...

-Philip, 52 years old, Caucasian man

I think about my mother and dad. I think about them every day.'

-Zach, 59 years old Caucasian man

(van Heumen, 2015)

Supporting social relations

Promoting social networks

Adults with ID need ongoing support to develop social networks

Acknowledge and maintain informal ties

Encourage and help build informal networks

Skilled inclusion/relationship worker

Continuous social network mapping (Bigby, 2008)

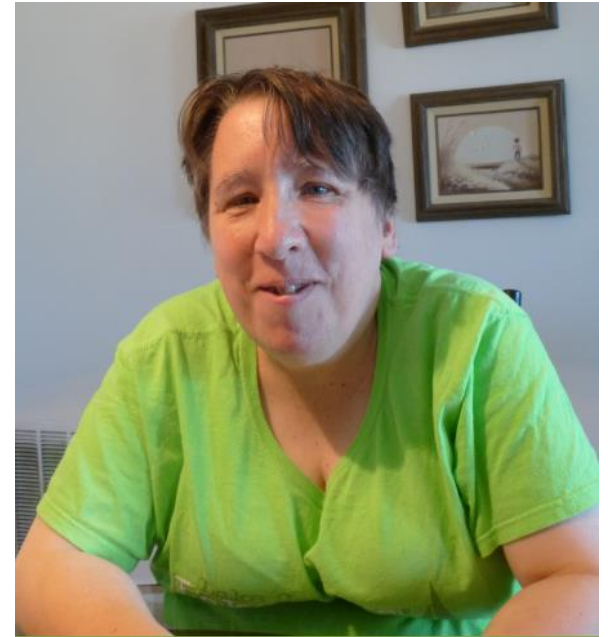
Enable meaningful social roles for adults with ID that align with their interests

Social network mapping

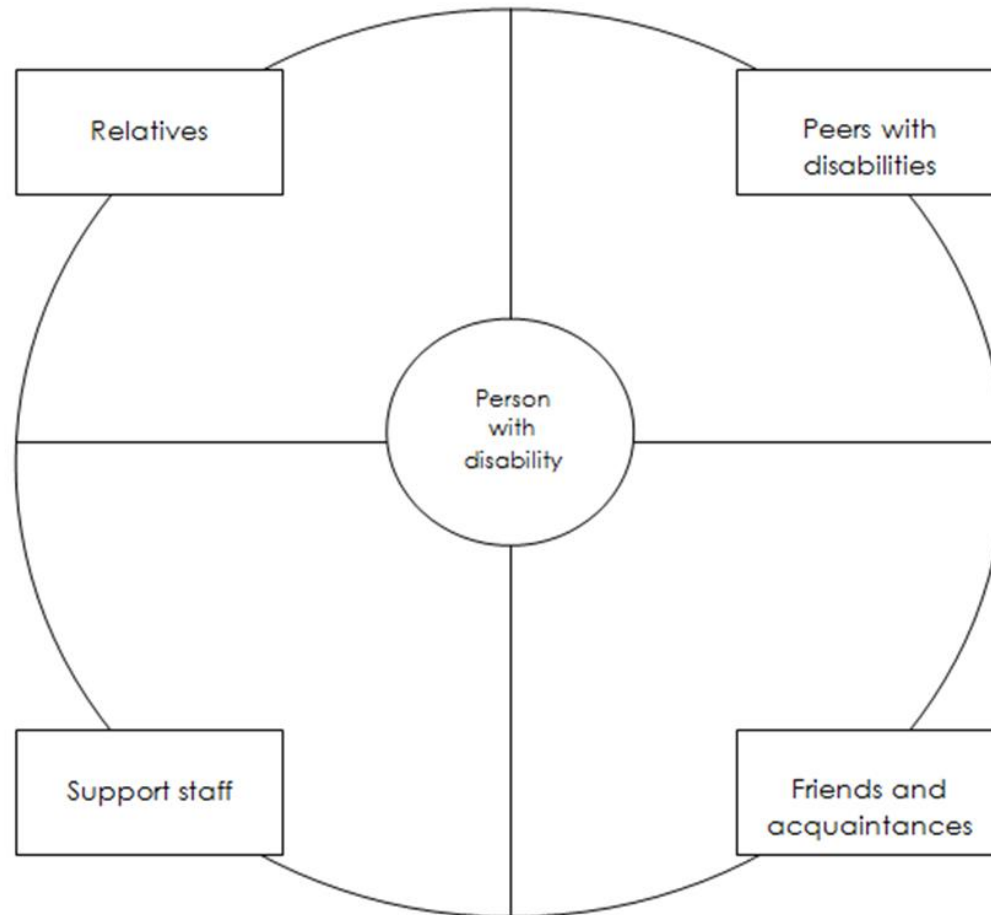
Genogram/family
diagram

Ecomap (Hartmann, 1978)

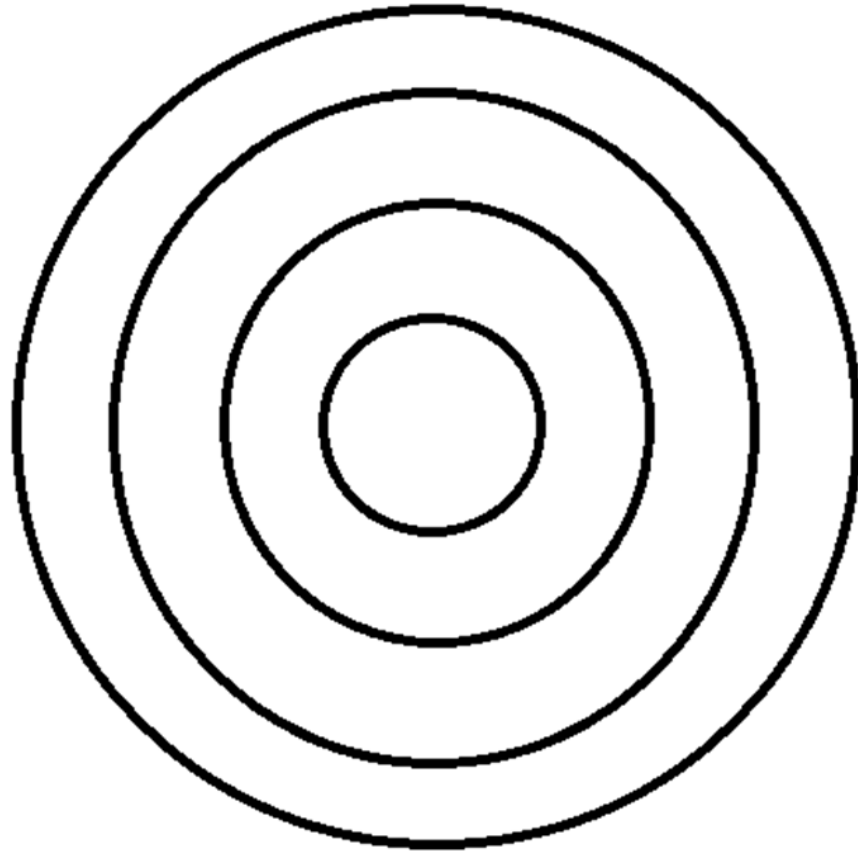
Social network maps



Social network mapping (I)



Social network mapping (II)



Social relations and future planning

Person centered future planning serves as opportunity to build informal relationships and supports (Factor et al., 2012; Heller & Caldwell, 2006)

Promotes self-determination

Involves and supports person with disability

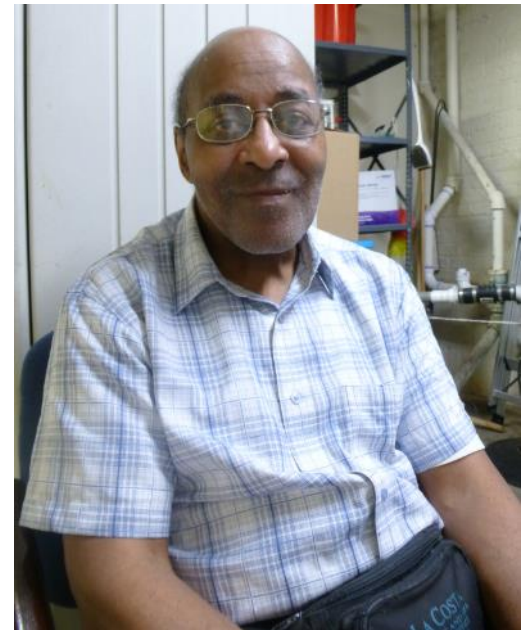
Creates meaningful engagement

Social relations and life stories

Older adults with ID often depend on others for their life history (and those important to them) not to be forgotten

Limited access to their own memories

Use life story work to inform everyday support (Meininger, 2005)



Life books

Scrapbook style, handwritten
Some templates used (Europe)

Life books address:

- Family
- Residential history
- Childhood
- Disability experience
- The present
- Future wishes
- End of life planning

Life books are never complete



Inclusive life story work

Explore creative methods that do not rely only on verbal communication

- Photo album
- Audio account
- Video report
- 'Memory box' (Aspinall, 2010)
- Poster (Hewitt, 2006)
- Life line (van Heumen, 2015)

Explore life stories by focusing on opinions and emotions instead of facts (van den Brandt-van Heek, 2011)

Questions

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